



The cohort effect in studies related to differences in psychosocial functioning of women with Turner syndrome

Efekt kohorty w badaniach różnic w funkcjonowaniu psychospołecznym kobiet z zespołem Turnera

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Abstract

Introduction: The physical health deficits and psychological disorders of women with Turner syndrome (TS) are the deciding factors in their treatment, but also their own relation to their own and their family's experiences. This study aimed to find the differences in psychosocial functioning of TS women coming from two different generations. These differences show the cohort effect as change in personal functioning and quality of life.

Material and methods: In-depth interviews were conducted with 176 TS women and their parents to collect data. The first cohort was composed of patients up to the age of 29 ($n = 139$), and the second included patients aged 30 or above ($n = 37$). Fifty-two variables, important from the point of view of health and quality of life, were analysed in two age groups. The paths models were compared to analyse differences between the cohorts.

Results: Belonging to a particular age cohort significantly affected the variance of the biomedical variables tested, which seems to be related to the therapeutic procedure due to an earlier diagnosis and treatment for younger patients. We also found differences in the number and strength of the correlations between the factors of psychosexual development, personal and family resources, socio-economic life, and professional or educational activity.

Conclusions:

1. The psychosocial functioning of TS women changes over time. This is a kind of illustration of the cohort effect.
2. Medical aspects of Turner syndrome may remain in connection with the psychosocial functioning of patients, and determine their quality of life.
3. Psychosociological resources are more complex and involved in younger women with Turner syndrome.

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Key words: psychology; cohort effect; Turner syndrome

Streszczenie

Wstęp: Deficyty zdrowia fizycznego i zaburzenia psychologiczne kobiet z zespołem Turnera (TS) decydują o sposobie leczenia, ale również o stosunku pacjentek do samych siebie, doświadczeniach rodzinnych i relacjach społecznych w środowisku ich życia. Celem pracy było pokazanie różnic w psychospołecznym funkcjonowaniu kobiet z TS pochodzących z dwóch różnych generacji. Ujawnienie ich dowodzi efektu kohorty, czyli zmian w funkcjonowaniu i jakości życia.

Materiał i metody: Metodą wywiadu bezpośredniego zebrano dane od 176 kobiet z TS i ich rodziców. Pierwszą kohortę stanowiły kobiety w wieku do 29 roku życia, ($n = 139$), drugą w wieku 30 lat i starsze ($n = 37$). Określono 52 zmienne dotyczące funkcjonowania psychospołecznego, jakości życia i aspektów medycznych. Dane te przeanalizowano w dwóch grupach wiekowych. Porównywano modele ścieżkowe różnic pomiędzy kohortami.

Wyniki: Przynależność do określonej kohorty wiekowej istotnie zróżnicowała wariancję testowanych zmiennych biomedycznych, co było związane z wcześniejszą diagnozą i leczeniem młodszych kobiet. Wykazano też różnice w liczbie i sile korelacji między czynnikami rozwoju psychoseksualnego, zasobami osobistymi i rodzinnymi, statusie społeczno-ekonomicznym, aktywności zawodowej lub edukacyjnej.

Wnioski:

1. Psychospołeczne funkcjonowanie kobiet z TS podlegają zmianom w czasie historycznym, co stanowi ilustrację efektu kohorty.
2. Aspekty medyczne pozostają w związku z psychospołecznym funkcjonowaniem pacjentek z TS i wspólnie wyznaczają jakość ich życia.
3. Psychosocjologiczne zasoby są bardziej złożone u młodszych kobiet z zespołem Turnera.

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Słowa kluczowe: psychologia; efekt kohorty; zespół Turnera



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Introduction

Turner syndrome (TS) is caused by a chromosomal abnormality in which all or part of the X chromosome is absent in females [1]. TS occurs in one in 2,500 live-born females [2]. Prenatal development is typically normal. The reproductive system undergoes degradation later. A low level of oestrogens and a high level of gonadotropins commonly cause abnormal menstruation, poor breast development, and extremely low fertility in TS patients [3]. Women with TS are about 20 cm shorter and display other physical features. TS women engage in sexual activity rarely and also start later in life. Patients also suffer from the symptoms of oestrogen insufficiency caused by the lack of hormonal replacement therapy earlier than the average age of menopause in the general population [4]. Ovarian agenesis and characteristic symptoms result in functional disorders which place an extra psychological burden on patients [5, 6]. On the other hand, sometimes psychological stress can influence gonadal function [7].

The neo-functional approach in developmental psychology emphasises psychological development as a process of constant adaptation, which consists of selecting goals, looking for optimal ways to attain those goals, and using compensation to react to hazards and limitations in personal resources [8]. The psychosocial functions and well-being of patients also depend on a patient's developmental history, life roles and the spectrum of social attitudes towards those with genetic disorders. These attitudes range from rejection, isolation and marginalisation, to tolerance, acceptance and constructive integration [9].

Little is known about the different individual trajectories of TS development in women in terms of social context and upbringing (i.e. family). Research has shown a tendency towards affective disorders [10].

To analyse the psychological functions of TS women, it seems important to take into account their age and year of birth or, in other words, the cohort to which they belong [11, 12]. These factors also determine some important social changes that are significant from the perspective of TS patients [13, 14]. It is also very important to determine how the patient's parents reacted when the patient received the diagnosis, how the patient reacted to the diagnosis, who was present, and how they supported the patient, what the parents thought, to what extent they felt guilty, and how they coped with the situation cognitively and emotionally, in what way the disease affected family relations, and what social attitudes the patients and their families faced [15].

The aim of this study was to analyse the social, psychological and familial aspects of women with Turner

syndrome in terms of their age and the period of their lives in which the empirical data was collected.

Material and methods

Empirical data was collected from 176 women with TS and from their parents, from 1995 to 2011. The data was processed according to a standardised medical history. The data collected was based on 52 variables that are specific to this study. These can be divided into four broad categories: biomedical parameters, personal resources, selected intrapsychic aspects, and family factors.

The empirical distribution of frequency was the statistical calculation used with regard to the patient's age (Fig. 1). Three age groups became apparent when the position measurement parameters, i.e. median (Me) and the 75th percentile (Me = 22 years old; Pe = 29), were applied. These groups were: adolescent patients up to 22 years old (Group A), young adult women aged 23–29 (Group Y) and adult women aged 30–53 (Group M). The three age groups were organised into two generational groups (cohorts). The first cohort was composed of patients up to the age of 29 ($n = 139$), and the second cohort included patients aged 30 or above ($n = 37$). Although this division differs from traditional arrangements, it was justified by empirical distribution and aspects of atypical development processes.

Three stages of development and two cohorts formed the basis for further analyses. Biomedical variances of interval variables were tested using ANOVA or t-test for independent samples. A t-test was applied with reduced degrees of freedom to account for a significant deviation from the normal distribution and the lack of variance homogeneity as determined using Levene's test. The Games-Howell test with the assumption of variance inequality was used to determine the statistical differences between the three age groups. The Kruskal-Wallis non-parametric rank based on χ^2 statistics was applied to analyse the differences in psychological, sociodemographic and family variables (nominal and ordinal variables) related to the age and generational groups. Spearman's rho was used, based on the variance in the number of concordant and discordant ordered pairs, to establish rank correlation between variables. The significance level was $p < 0.05$. The calculations were conducted using the SPSS program for PC.

Results

Results are presented in Tables I–III for the three phases of development. Figure 1 shows the frequency distribution of women with TS at a particular age. Correlations

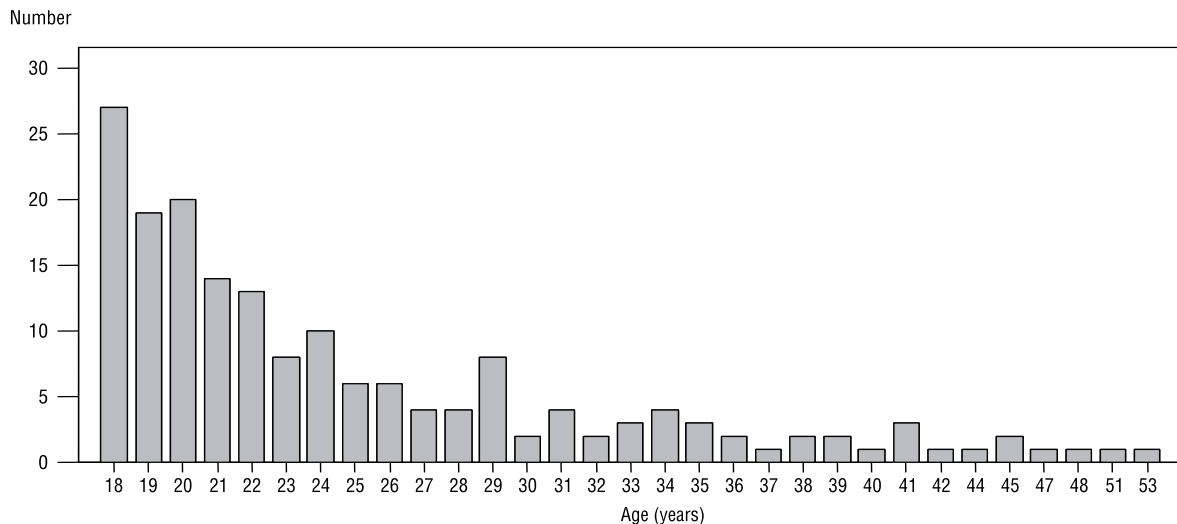


Figure 1. Frequency distribution of women with Turner syndrome at a particular age ($n = 176$)

Rycina 1. Rozkład liczby pacjentek w określonym wieku życia ($n = 176$)

Table I. Basic biomedical parameters in the three age groups

Tabela I. Wartości podstawowych parametrów biomedycznych w trzech grupach wiekowych

Phase of development	Parameters	Age of symptom onset	Beginning of treatment	Age of menopauses' symptoms onset	Body mass [kg]	Height [cm]	BMI [kg/m ²]
A	N	93	89	18	95	95	95
	Range of results	17	19	8	47	38	25
	Me	6	13	17	45.4	144	21
	M	7.19	12.48	16.56	47.51	145	22.6
	SD	5.28	4.44	1.67	8.78	6.75	4.11
Y	N	42	45	15	46	46	46
	Range of results	17	27	14	45	37	15
	Me	9	13	20	50.2	145	23.47
	M	8.4	12.84	20.67	51.96	146	24.06
	SD	5.81	5.57	3.68	10.18	7.68	3.95
M	N	32	35	12	35	35	35
	Range of results	25	48	35	41.3	20.5	19.09
	Me	10	18	22.50	52	139	26.66
	M	10.2	22.51	25.91	52.91	140	26.68
	SD	5.64	12.69	12.03	11.11	6.34	4.93

Adolescent patients up to 22 years old (A), young adult women aged 23–29 (Y), and patients aged 30–53 (M). N — number; M — mean; Me — median; SD — standard deviation

of absolute values are inspired by path analysis [11] and were between 0.19 and 0.87 for the two cohorts. The values are illustrated in Figures 2 and 3 with the respective numeration of significant variables ranging from 1 to 52 for the first, and from 1 to 43 for the second cohort. For the sake of clarity, the pictures present only the relations that were, on average, equal to or greater than 0.30.

At the beginning of the study, the accuracy of the established age criterion was tested according to the following parameters: the age when the first TS symptoms were noticed, the age when treatment began, the age when the first symptoms of oestrogen insufficiency began, body mass, height and BMI (Table I). These tests led to the expected results (Tables II and III). There was significant inconsistency in the variance of tested biomedical vari-

Table II. Differences in groups according to age/phase of life (with the assumption of a lack of equality of variance in compared groups)**Tabela II.** Zróżnicowanie w grupach wyznaczonych wiekiem/okresem życia (przy założeniu braku równości wariancji w porównywanych grupach)

Variables	Levene's test F	Significance	t	df	Significance
Karyotype	2.62	0.107	0.7	56.09	0.48
Age of symptom onset	0.41	0.522	-2.65	47.66	0.01
Beginning of treatment	69.91	0.0	-4.67	39.11	0.0
Age of menopause's symptoms onset	23.41	0.0	-2.35	12.79	0.04
Body mass	1.56	0.213	-2.29	50.29	0.03
Height	0.04	0.846	3.59	60.81	0.001
BMI	3.31	0.070	-4.24	50.48	0.0

Table III. Multiple comparisons conducted by means of the Games-Howell test in the age groups of patients (The table does not include the recurring results of comparisons)**Tabela III.** Porównania wielokrotne testem Gamesa-Howella w trzech grupach wiekowych (tabela nie uwzględnia powtarzających się efektów porównań)

Variables	(I) phase of development	(J) phase of development	Mean variance (I-J)	Standard error	Significance
Age of symptom onset	A	M	-3.03	1.14	0.028
Beginning of treatment	A	M	-10.03	2.19	0.0
	Y	M	-9.67	2.30	0.0
Age of menopause's symptoms onset	A	Y	-4.11	1.03	0.002
	A	M	-9.36	3.49	0.051
Body mass	A	Y	-4.45	1.75	0.034
	A	M	-5.4	2.08	0.033
Height	A	M	4.41	1.28	0.003
	Y	M	6.12	1.56	0.001
BMI	A	M	-4.08	0.93	0.0
	Y	M	-2.62	1.01	0.033

Patients up to 22 years old (A), young adult women aged 23–29 (Y), and patients aged 30–53 (M)

ables. The most consistent variables were the karyotype, the age, the phase of life and inclusion into a specific cohort (strongly correlated, though no identified variables).

The most common feature in the older cohort was increased spinal problems, while no other differences in health variables were found ($\chi^2 = 26.64$; $df = 1$; $p < 0.001$). The anamnestic data did not provide any evidence related to differences in the childbirth process, medical history or other childhood problems.

In the younger patient groups (A and Y), the first symptoms of TS were noted during childhood (Me: age 6 for A and age 9 for Y), and treatment was initiated five years earlier than for those in the oldest patient group (M). Younger patients had a better BMI, which may be the consequence of better therapeutic care. A difference was also observed regarding the onset of menopause symptoms in women from the younger

age groups (A and Y), which occurred at the average age of 17 and 20, respectively; while those in group M typically experienced symptoms at age 22.5.

The different age groups did not diverge significantly in relation to family structure. However, the data illustrated a difference in the patients' family resources based on the job status and work activity of the parents (for mothers: $\chi^2 = 23.66$; $df = 8$; $p < 0.003$; for fathers: $\chi^2 = 24.55$; $df = 8$; $p < 0.014$). There were more qualified workers in the younger generation of parents ($\chi^2 = 9.7$; $df = 1$; $p < 0.002$) and more of their daughters were working or were students ($\chi^2 = 6.7$; $df = 1$; $p < 0.01$). Older patients more often felt the need to change their lives significantly than younger patients ($\chi^2 = 6.5$; $df = 1$; $p < 0.001$).

The most striking difference between the younger and older generations (first and second cohorts) was

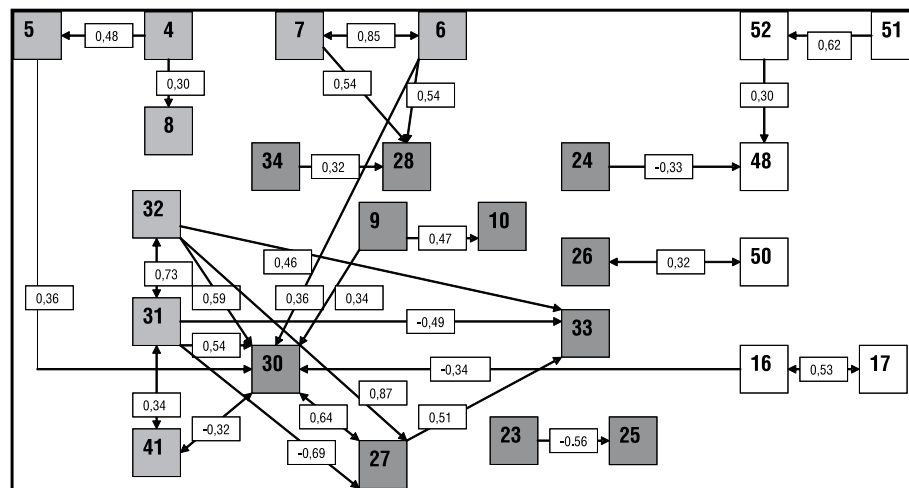


Figure 2. A path model for the first cohort. The grey colour indicates the factors of personal and intrapsychical resources: [4] — the patient's education, [5] — the patient's career, [6] — the patient's socioeconomic status, [7] — work activity, [8] — the feeling of handicap, [31] — independence of accommodation, [32] — being in a partnered relationship, [41] — the need for autonomy. The dark grey colour indicates the medical factors and the aspects of psychosexual development: [9] — the age at which the symptoms were noticed, [10] — the age at which the patient was diagnosed with TS and the age of treatment onset, [23] — spontaneous / initiated menstruation, [24] — normal / disappearing menstruation, [25] — normal/slowed sexual development, [26] — libido, [27] — sexual activity, [28] — the age of sexual initiation, [30] — the level of sexual satisfaction, [33] — complaints concerning infertility, [34] — the age at which symptoms of menopause started. The white colour indicates the factors of family resources: [16] — mother's educational background, [17] — father's educational background, [48] — mothers' opinions about the influence of TS on their daughters obtaining qualifications, [50] — mothers' opinions about the influence of TS on their daughters' future, [51] — the appropriate estimation of the significance of the TS problem, [52] — the level of the mothers' acceptance of their daughters' condition

Rycina 2. Model ścieżkowy dla pierwszej kohorty. Kolorem szarym zaznaczono czynniki zasobów osobistych i intrapsychicznych: [4] — wykształcenie pacjentki, [5] — wyuczony zawód, [6] — status społeczno-ekonomiczny, [7] — aktywność zawodowa, [8] — poczucie upośledzenia, [31] — samodzielność mieszkania, [32] — posiadanie partnera, [41] — potrzeba autonomii. Ciemno szarym kolorem oznaczono czynniki medyczne i aspekty rozwoju psychoseksualnego: [9] — wiek zauważenia objawów TS, [10] — wiek diagnozy i początku leczenia, [23] — miesiączka spontaniczna/wywołana, [24] — przebieg miesiączki prawidłowy/zanikający, [25] — rozwój płciowy o czasie/opóźniony, [26] — libido, [27] — współżycie seksualne, [28] — wiek inicjacji seksualnej, [30] — satysfakcja z życia erotycznego, [33] — skargi na bezpłodność, [34] — rok życia wystąpienia objawów przekwitania. Białym kolorem oznaczono czynniki zasobów rodzinnych: [16] — wykształcenie matki, [17] — wykształcenie ojca, [48] — opinia matki o wpływie TS na zdobycie zawodu przez córki, [50] — opinia matki o wpływie TS na przyszłość córek, [51] — docenienie wagi problemu TS przez matki, [52] — stopień pogodzenia się matek z chorobą córek

found regarding their psychosexual life. This is demonstrated by the age of first sexual activity, which occurred at age 19 for group A, 22 for group Y, and 24 for group M ($\chi^2 = 35.1$; $df = 1$; $p < 0.001$), and whether the patient had a partner either by marriage or co-habitation ($\chi^2 = 18.2$; $df = 1$; $p < 0.001$). The 20 youngest women emphasised the role of early endocrinological treatment used to initiate menstruation. This feature significantly divided the generations ($t = -3.045$; $df = 130.68$; $p < 0.003$). Menstruation (normal/premature symptoms of menopause) increased the urge for a life-change ($\chi^2 = 3.67$; $df = 1$; $p < 0.042$). Sexual experience and sexual satisfaction significantly differed in the two research cohorts ($\chi^2 = 49.35$; $df = 1$; $p < 0.01$) and the women who declared the highest level of sexual satisfaction were in group Y (age 23–29; $\chi^2 = 8.46$; $df = 2$; $p < 0.015$). The lack of a sexual life occurred for various reasons and was not specific to age or a given cohort. The most common explanations for the lack of a sexual life were immatu-

rity ("still too young") and religious reasons, while the women's feeling of illness was a less significant factor. A content analysis of the interviews showed that intrapsychic problems that were connected with sexual experiences affected older patients more than younger ones ($\chi^2 = 19.4$; $df = 1$; $p < 0.01$). In general, the younger age group initiated sexual activity at a younger age.

The link between the attributed causes of TS and the guilt felt by mothers was relevant, but it is mostly related to the mothers of patients in the younger cohort ($\chi^2 = 7.27$; $df = 1$; $p < 0.026$). This link also contributed to earlier treatment ($\chi^2 = 31.23$; $df = 20$; $p < 0.052$). It is worth mentioning that the mothers' belief in the hereditary source of the condition may be a stressor in family relationships, as the patients whose mothers felt guilty become more isolated from others ($\chi^2 = 6.47$; $df = 2$; $p < 0.039$).

In summary: the empirical data was analysed as two spheres to reveal a cohort effect. The first sphere

in younger women (Fig. 2). The intellectual climate (16*, 17*) affected the younger patients' satisfaction as sexual partners (30*). The mothers' attitude towards the reliability of medical data related to their daughter's condition was also important (51*) and was positively correlated with the acceptance of their daughter's condition (52*). The opinions of mothers regarding their daughter's future, especially those related to the effect of TS on their daughter's existential and career independence, were of great importance (48*). These correlations were based on their perception of the evidence concerning the abnormal sexual development processes of TS patients and the necessity for treatment initiation (23*, 24*, 25*). The mothers also worried about their daughter's future (50*) in relation to their daughter's libido (26*).

The family portrait of the second cohort was less complicated (Fig. 3). The patient's sexual life was the only factor that was linked to the mother's and father's level of education (17*). This may be associated with a deeper understanding of human erotic desires. It may also be associated with the obvious disinterest to the sexual aspects of the disorder and the sexual life of daughters suffering from TS. This trend was observed in the families of older patients and in the absence of parental anxiety concerning the patient's upbringing during adolescence.

Family factors were related to psychosexuality in both generational groups, but these factors were more numerous and more dominant psychologically in younger women. For example, the higher socioeconomic status, independence, and work or educational activity of younger patients (5*, 6*, 7*) delayed sexual activity initiation (28*) (Figs. 2 and 3), which is in accordance with the general psychosexual development trend of Polish women [17]. Moreover, numerous sexual and erotic factors in younger patients (26*, 27*, 28*, 30*, 33*) were involved and were connected to a greater extent with many aspects of personal and family resources (6*, 7*, 16*, 31*, 32*, 41*, 48*, 50*). The intersection between clinical and existential problems also appeared to be significant. This intersection was present in both cohorts, and was based on companionship (32*), the level of sexual activity (27*), and the confrontation with infertility (33*).

A relationship between the urge to become autonomous, which was slightly stronger in the older cohort (41*), and one's living situation (31*) was noticeable in both groups. On the one hand, a level of autonomy may be expressed in the pursuit of existential independence, which, in turn, confirms independence in life. The younger patients maintained a stronger pursuit of autonomy (one-sided correlation with the patients' age: -0.40 ; $p < 0.001$). Their pursuits included not only the typical dreams of travelling, learning other languages and building a house, but also pro-social aims, such as helping elderly parents and establishing a charity.

Sexuality and erotic experiences, the need for autonomy and appropriate socioeconomic status defined the feeling of dignity for research patients. However, it is worth emphasising that autonomous tendencies in younger patients may work as a 'two-edged sword' [18]. Autonomous tendencies lead to loneliness in adolescents as more independence equates to more loneliness [19]. To some extent, the empirical evidence could show a negative correlation between the need for autonomy (41*) and sexual satisfaction (30*) in the first cohort.

Meanwhile, the pursuit of autonomy in the second cohort was linked with a late diagnosis and a late initiation of TS treatment (10*). This link is not easy to interpret. The link may prove the significance of early and appropriately presented diagnosis, as this may protect patients from the shock of a difficult truth that can cause emotional alienation [15].

In general, sexual activities occurred earlier in the younger age group. This fact causes anxiety in parents because sexual activity does not usually accompany socioemotional maturity and self-reliance in patients. As far as TS women are concerned, their sexual development arrives very early in life. This was shown by the age of first sexual activity in the three research groups. Those in group A first experienced sexual activity at age 16, those in group Y at age 20, and those in group M at age 25.

Therefore, the problem of early sexual initiation requires particular sensitivity and consideration. It can be assumed that conscious and safe sexual activity in TS women may be an important area that requires psychomedical help, and may be an indicator of quality-of-life. From a psychological viewpoint, being a sexual partner allows TS patients to feel feminine and protects them from a negative self-identity or loneliness. This viewpoint is vicariously confirmed by the fact that older patients more often felt the need to change their lives significantly than did younger patients. However, prospective orientation and readiness for change usually characterised younger patients more readily than older patients, which may demonstrate certain developmental patterns.

Conclusions

1. The psychosocial functioning of women with Turner syndrome undergoes changes over time. This is a kind of illustration of the cohort effect.
2. Medical aspects of Turner syndrome may remain in connection with the psychosocial functioning of patients, and determine their quality of life.
3. Psychological resources are more complex and involved in younger women with Turner syndrome.

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